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ABSTRACT

The manual discusses home based approaches to support families of developmentally disabled children. The first section presents in question and answer format the rationale for such support services. Succeeding sections address the following aspects: respite care, sitter/companion services: parent counseling, education, and training: in home workers: cash subsidy: and advocacy. The array model, in which a decision center would act as a broker for all the agencies and programs operating in that area, is proposed as the best model of service. (CL)

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A HANDBOOK FOR HOME-BASED SERVICES

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Maggie Kenney

December 17, 1979

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This handbook is intended to serve as a guide for concerned citizens, parents, and professionals who are searching for better ways to support the families of the developementally disabled.

TABLE OF CONTENTS

Introduction	1
Respite Care	3
Sitter/Companion Services	5
Parent Counseling, Education & Training	6
In-Home Workers	7
Cash Subsidy	8
Advocacy	8
References	9

1. What are Home-based Services?

Very simply, they are whatever services or supports that the family of a developmentally disabled person determines they need to better cope with the special needs of that family member. Such needs are not limited to, but may include the following: Respite care, sitter/companion services, parent education, counseling and training, recreation, adaptive equipment and architectural changes in the home, transportation, advocacy, cash subsidies, homemakers and other in-home workers.

2. Who are they for?

They are for any family who has a developmentally disabled member and who desires to maintain together as a family. Home-based Services should be offered without age or income restriction.

3. Why are these services important?

We are in the midst of a profound and wide-sweeping re-assessment of the way in which our society will view and treat persons with developmental disabilities. Traditionally, persons so identified were often isolated in large, custodial, public or private institutions. Since the 60s, public attention has been increasingly focused on the needs of minority groups, including the handicapped. It is now recognized that these individuals' rights as citizens do exist and must be protected. Therefore, agencies responsible for providing services to the developmentally disabled have been instructed to do so in the least restrictive and most normalizing setting. However, they are at the same time being asked to provide these services as economically as possible.

Services that will support and prolong the developmentally disabled individual's residence with their family meet all of these criteria--the natural home is almost invariably the least restrictive, most normalizing and least costly residential setting. In addition, the increased presence of developmentally disabled persons in the community will act as a catalyst for greater social acceptance and concern for their needs. There is much truth in the old axiom "out of sight, out of mind".

4. Why should agencies develop these services?

Community human service agencies experienced a period of rapid expansion in the last 60s and early 70s. This expansion era has been brought to an abrupt halt by recent successful efforts to limit public spending. As a result, many agencies are now faced with the prospect of reducing the number of clients served to survive the impact of rapidly escalating cost and fixed budgets.

This reduction may mean that many developmentally disabled individuals will not have access to residential and ancillary services in the community. One outcome might be increased admission to institutions. We believe a better outcome and one that is much more in line with the commitment to provide services in the least restrictive and most normalizing setting possible would be to re-allocate existing funds to develop services that would support the continued residence of these individuals with their own families.

Some agencies have been and are now offering Home-based Services. Unfortunately, these services are often seen as frills and are poorly coordinated. Agencies must adjust their priorities to provide the first and most intensive intervention to the family. No longer should parents face an all-or-none situation where they may either struggle along alone or place their child outside the home where all of his needs will be provided for. Parents should be encouraged and aided to remain responsible for their children. Where Home-based Services are available, it may even be feasible for children who have been previously placed in community or institutional residential settings to return to their natural families.

5. Why should parents advocate for and use these services?

Even the best or institutional setting cannot provide the emotional support and personalized care that a child receives while growing up in his or her own family. Most parents can be taught the special skills that are necessary to effectively care for their developmentally disabled children and these parents can maintain them at home provided they receive adequate support.

6. Why should taxpayers pay for these services?

In terms of human costs, Home-based Services are a good deal. Families are not separated and the rights of developmentally disabled persons are not infringed. In terms of economic costs there is a great potential savings when compared to the lifetime cost of institutional care. Many developmentally disabled persons can be trained to become partially or wholly economically self-sufficient.

7. How should these services be organized?

Continuums of human service are popular today but are not readily applicable to Home-based Services. Families will have widely varying needs and resources. They will not all require the same kind or the same number of supports. Families may require different services at different times during their handicapped child's life.

A better model of service would be the array model. Families would shop for and select the support they needed from the existing array of services.

To assist the family in the selection and obtainment of desired services, a local decision center could be established. This decision center would act as a broker for all the agencies and programs operating in that area. The decision center would have three basic functions:

a. to act as a clearing house for all agencies and programs in this area. The decision center would rate programs for quality and effectiveness.

b. to provide a place where families would go to state their problem and to be evaluated to determine need and eligibility for services.

c. to function as a decision center where family's needs would be matched with available services. The family would be offered suitable (appropriate, least restrictive and cost beneficial) options. The family would then chose between the offered options.

This model of service would eliminate much of the bureaucratic inefficiency and waste we currently suffer and would encourage the development of new, small, innovative service programs suitable to use by families.

I. Respite Care

The word respite means a temporary period of relief or rest from duty. All parents need a respite from their children. Parents need to spend time pursuing their own interests, enjoying each other's company, attending social functions and dealing with family emergencies. However, parents of developmentally delayed children frequently have a difficult time finding someone who is willing and competent to care for their child. Relatives and neighbors may be available to care for normal siblings but not the handicapped child, and parents may be reluctant to leave their handicapped child with an untrained caretaker. As these children reach adolescence and adulthood, it becomes even more difficult to find temporary caretakers.

Respite care is an essential component of any comprehensive Home-based Services program. Many parents have sought a residential placement for their child because they feared that they were neglecting their other children, or because they were unable to find some temporary relief to help them through a family crisis. Many parents are fearful of being hospitalized and will neglect their own health needs because there is no one else to care for the child. Often parents are not able to go out for an evening or attend any social function together because one parent must always stay at home to care for the developmentally disabled child. For these parents, a simple outing can be an impossibility.

Respite care is not a new idea but it is only within the last three years that it has become available. Many agencies and advocacy groups in this country as well as in Canada and England are developing this service. There are presently five basic models.

A. In-Home Respite Care

In this model, specially-trained respite providers (preferably persons who already know the family) go to the home while the parents are away. This design is inexpensive and is the least disruptive for the developmentally delayed person since they remain in their own home and can follow their usual routine. This model is especially good for individuals who require a barrier-free environment or who use non-portable adaptive equipment.

However, it is sometimes difficult to recruit respite providers who are willing to move into the family's home. This model also overlooks the fact that some parents would like to stay home for a vacation or need to stay home during a crisis or illness. Also, oftentimes the handicapped person would enjoy a change of scene and an opportunity to meet new people in a different setting.

B. Out-of-the-home Respite Care (respite homes)

Here the trained respite provider functions as a temporary foster home. The developmentally delayed person moves into the home of the respite provider. This model is also inexpensive and offers the client a chance to develop ongoing relationships with people outside of his or her immediate family.

C. Respite Group Home

Such a group home would be designed to exclusively provide respite care. Although not a widely-used model, it is one that is essential for serving individuals who have serious behavior problems. Typically, persons who are dangerous to themselves or others or who are destructive of property will not be welcomed in a respite home. They will need placement in a specialized facility that can provide more staff and more structure to deal with their problem behaviors. A respite program that has such a specialized facility in addition to the in-home and/or out-of-the-home providers should be able to serve almost any of the developmentally delayed who are living in their community. Without such a facility, the parents who need respite care most may be the ones who can't get it.

Disadvantages to the respite group home model usually revolve around cost. If some space in the group home is reserved for emergencies only, then the unit cost of care in relation to actual usage will be very high. On the other hand, if all spaces are regularly filled, then there will be no capacity to respond to real emergencies. In addition, there is a tendency for such programs to become filled with medium-to-long stay clients who are awaiting the opening of a more permanent type of residential placement (i.e. parent dies, family disintegrates, another program "dumps" a client into this program). Under these circumstances, a respite group home can quickly become a pre-residential group home.

Another limitation of this model is its centralization. In serving a large geographical area, arranging transportation to and from day programs will be problematic if you rely on only one centralized location.

The respite group home can be effective provided that entrance and exit criteria are well defined and respected, and it is supplemented by in-the-home or out-of-the-home respite providers.

D. Group Home Respite

Under this plan, one or two beds at an existing group home are reserved for community respite clients. This is a relatively inexpensive and practical model in areas where these group homes are open. However, it does have some serious drawbacks. Typically, the respite client must meet some compatibility criteria such as age, sex, type, or degree of handicap. Also, the staff and other residents of the group home will frequently view the respite client as "extra work" or as an intruder. Usually, the respite client must adapt to the routine and expectations of the group home without much consideration of his or her individual needs or preferences.

E. Institutional Respite

Some public and private institutions maintain a few respite beds. The advantages to this model are few and are far outweighed by the disadvantages. Invariably an admission to such a facility is expensive, disruptive of the individual's attendance at his or her day program and overall life, and preceded by much paperwork and red tape. Interestingly enough, although many of these facilities call themselves or are associated with hospitals, they usually will not accept anyone who is sick on a respite basis.

Almost without exception, such a move would entail a difficult adjustment for anyone who is accustomed to living in his or her own home. This model should be viewed as a last resort in a dire situation and should motivate a community to develop better alternatives.

II. Sitter Services/Companion Services

Sitter/companion services are distinguished from respite care by their shorter duration--usually 10 hours or less. Sitter services refers to temporary care of children, while companion services refers to the temporary care of adults. Sitter/companion services are very popular with parents and very inexpensive. A sponsoring agency may initiate such a program by presenting a training course for sitters/companions. Such training generally covers these topics: Introduction to developmental disabilities, behavior management techniques, positioning, handling and use of adaptive equipment, self-help and daily living skills, seizures, medications and first aid, and communication. The sponsoring agency may take advantage of free public service announcements on radio and television as well as news releases in local newspapers to advertise the training workshop and attract participants.

Once trained and screened, the sitter/companion names are placed on a registery. Parents may phone into the registery and receive a list of names of sitters/companions in their area. Parents usually contact and pay the sitter/companion directly.

Another model for sitter services is called Extend-a-Family. This program was developed in Ontario, Canada and consists of a group of parents of developmentally disabled children. These parents have organized themselves into a type of cooperative sitting arrangement in which they trade sitting services with each other rather than pay for them.

Both the Extend-a-Family and sitter/companion registery programs provide an inexpensive and accessible service that is very responsive to the needs of individual families. The development of such a service should be a first step in any good home-based services plan.

III. Parent Counseling, Education and Training

A. Parent Counseling

Living with a developmentally disabled child will place additional demands and stresses upon the family. This additional stress may accentuate any pre-existing problems and may strain the marital relationship. Parents will commonly experience conflicting feelings of grief, shame, anger and chronic sorrow over the condition of their child. Parents need access to sensitive and trained counselors who can help them to express and resolve these feelings and work toward a fuller acceptance and integration of the disabled child into the family.

B. Parent Education

This is a very broad area that includes any knowledge that would enable the parent to better understand and care for their developmentally disabled child. Parents may need education in just a few or many areas.

Parent education includes but is not limited to: information on the child's particular disability, first aid, control of seizures, use of adaptive equipment and prosthetic devices, positioning and handling, feeding techniques, nutrition, basic child care and child development, homemaking, communication and sign language, sexuality.

C. Parent Training

Many children with developmental disabilities have a difficult time mastering the simple skills involved in every day living. Many of them will need physical therapy, adaptive equipment and intensive individualized education. However, this does not mean that their parents must abdicate all responsibilities for their education to professionals. On the contrary, these children are even more in need of consistent and careful training at home. The skills needed to teach these children are not so complex that the average parent can't learn and use them.

Parent training should be more than a presentation of general information on handicapping conditions. Beyond understanding the child's condition, parents need to learn specific teaching techniques that will allow them to aid their child's growth towards greater independence.

Parents generally need to learn how to teach their children new skills, and deal with behavior problems. The most effective strategies for both teaching new skills and correcting behavior problems involve behavior modification. Parents can be taught to successfully apply the principles of behavior management at home. Classes may be arranged for individual or group training sessions.

An integrated approach to parent training has been developed in Utah. Professionals at the Exceptional Child Center cooperated with the Extension Service at the Utah State University to disseminate carefully prepared and specially designed parent training packets. Parents may order a packet on a particular skill through the mail and then have access to a toll free telephone line to consult with the staff at the Exceptional Child Center. Parents are also visited by County Extension Agents. This has been an effective and economical method of extending training to families in rural and remote areas.

IV. In-Home Workers

These are specially trained persons who go into the home of a developmentally disabled child to provide hands-on training and assistance. Generally these workers are paraprofessionals who are supervised by a professional who is also involved with the family. Such an in-home worker is in an ideal position to repeatedly demonstrate behavior management and skill training techniques. Being in the home with the parents at regular intervals, they may reinforce what the parent is learning in their parent training class. In addition to this teaching function, the in-home worker perform the routine tasks associated with the daily care of the developmentally disabled child. Frequently the care of such a child places extraordinary demands on the parents' time and energy. In-home workers can alleviate parent burn-out by providing a portion of the day-to-day care. They may also allow parents to spend time with their other children.

In-home workers may be assigned on a temporary basis to assist a family during a particularly difficult time such as parent illness, divorce, or implementation of behavior change program, or they may be assigned as an ongoing support to that family.

It is very important that in-home workers respect the integrity and privacy of the family. Optimally these workers should be directed by the goals and needs that are identified by the family, and although employed by some outside agency should remain accountable and responsive to the family.

In-Home Workers for Adults

Adults with developmental disabilities may need some in-home assistance to make the transition from their family here to independent living. In-home workers could be called upon to assist the developmentally disabled adult with homemaking, banking, community access, job finding or other skills. Again, this may be a temporary or ongoing assignment. Particularly in need are the developmentally disabled who are parents. Many will need assistance to cope with the added responsibilities of child rearing.

V. Cash Subsidy

Several states currently offer cash subsidies as a way of encouraging and aiding parents to maintain their developmentally disabled children at home. These cash subsidies allow the parents to purchase needed services for the child. Such a subsidy would coordinate well with the decision center organization model and would greatly reduce the need for the many separate government entities that currently funnel piecemeal funds to individuals and agencies. Direct payment for services from family to agency would greatly increase the agency's accountability to its consumers.

VI. Advocacy

Advocacy means support. Parents of developmentally disabled children are frequently misunderstood by well-intentioned friends, relatives and professionals. Upon the birth or diagnosis of a handicapped child they may feel alone and bewildered. At such times, and throughout the child's life, his or her parents will need the support and concern of others.

A highly successful network of advocacy has been developed by the Pilot Parents program. This program is composed of parents of developmentally disabled children who have learned through their own experience that raising such a child can be rewarding. These experienced parents complete special training to enable them to assist and guide new parents of handicapped children. These pilot parents are able to offer the new parents emotional support and understanding as well as factual information about developmental disabilities and the programs and services that are available in their community.

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